

Burton Blatt: National AAMD Speech, 1984

Audio Transcript

Part One

I thought I'd play this song written by a very fine young man in Philadelphia, Carl Williams, who's one of you, works with the disabled, and this one is called *Euthanasia*. Other things he's done are equally provocative. I'm going to speak for, oh, about an hour and 10 or 15 minutes. And if you have anything to say, those are still here, I'd welcome your comment or question.

Talking about the progress paradox in mental retardation... I recently read a biography of the great, now-deceased artist and photographer Diane Arbus, who once said about a photograph what I'm going to say about mental retardation, that it's a secret about a secret. The more it tells you, the less you know.

And that's fundamentally what I'm going to get at with these ideas on with a progress paradox and the science fantasy. For example, the question of advocacy continues to come up with programs loaded with sessions on advocacy. And here is, I think, a quintessential example of where too much of a good thing is not a good thing. After all, advocacy is wonderful, to work on behalf of another human being as if you're working on your own behalf.

But if people need a lot of it and they need it continuously, that fact also informs us about our society: That people need others to work on their behalf, people need others to protect them. And so to the degree that advocacy is important, a necessary component of our work to that degree, the society is imperfect. In a more perfect society, we wouldn't need advocates. We wouldn't need people to demand entrance of children into schools or demand good programs or normal opportunities for living in the communities. That these would be guaranteed, that would not require special conditions or special people to advocate for.

The same with residential programs. Of course there are some people who need residential programs outside of their own homes. There'll always be some who don't have homes for whatever reasons. But to the degree that more and more people need residential programs to that degree is not progress we're making but in some way it's a reflection of a very imperfect society.

And that's why when you walk around the corridors of these meetings here and elsewhere, meetings of this sort, the State Commissioner and Superintendent they just brag in how their institution has been reduced in size. And this week I heard that Michigan's institution is going to close down in a couple weeks. And there's a great feeling of euphoria in Michigan that they're finally going to close down that institution, as where the Governor informs us in New York we're going to close down one of the supposed infamous institutions in New York.

Now that's the tipoff. President of Harvard University or Syracuse University isn't crowing when fewer people come to their institutions. They're saying, "My heavens, what a wonderful school we have. We're able to accept fewer people, and we're able to prohibit people from coming in. Well, gee whiz, maybe if we do our work well in 20 years or 30 years, Syracuse University will be able to close its doors forever." We don't say that.

In fact, when presidents of universities start losing enrollment, they take the president by the ear and they throw them out of the university. When superintendents of institutions reduce enrollment, they give them awards from the American Association on Mental Deficiency. So here we have a—by the way, this is all preliminary to my next preliminary set of remarks. Here we have a field where nothing succeeds like failure, nothing fails like success. And you've got to understand the progress in this field in terms of these paradoxes, otherwise we're going to mislead ourselves.

I like to start my diatribes with a recounting of some of the things I see in the news because it's an imperfection of my character or stature or intelligence, I seem to learn more in periodicals like the New York Times than the American Journal on Mental Deficiency about mental retardation. So we'll look at some of the news and some of the events and some of my mail. I get interesting mail. Oh, I got a letter from President Reagan the other day. I want to read it to you. What are you laughing about? Here it is you. Some of you might have gotten a similar letter. I also got a letter from Fritz, and Jess, and Gary, but this one's from the president. It's good to throw these names around. He's already the president. You don't know who the next one's going to be. Although we know, don't we?

"Dear Mr. Blatt, I'm very grateful for all you've done to support me over the past three years. As I've worked to rebuild our economy and our defenses, together you and I have brought our nation away from the brink of economic disaster facing us when I took office in 1981." And he goes on to give me lots of compliments about my support for him. That's why I'm counting on my answer to his survey and financial contributions to his campaign. "Nancy and I can never thank you enough for your support and encouragement, and I pray I can count on you again. God bless you." How did he know I'm so supportive? I didn't even know that.

This is not the only letter I received from, as I told you, of people interested in the presidency, and as a result of all of this concern for my support, I have decided to become a candidate myself, and I'm announcing my candidacy for the presidency of the United States today. I did last year, I think, and nobody took it seriously. I think it's time you folks took my candidacy seriously. I want to be President of the United States. I want you to go out and support me. It's a little late, so I'm not going to enter the primaries, and I'm not going to go to the convention, but I think it will all work out.

We've got a government today that's different than previous governments. The last government or two in America didn't know anything about the poor and the disenfranchised and the handicapped. We were worried about that we complained to Mr. Carter and all of his predecessors. They didn't know about the barriers to access, and they didn't know about the disenfranchised children and people were hurt in institutions. Well, this government is different. The current government is different. This government doesn't want to know, and that's the difference. That's a very serious difference. I don't know what we could do about it. I'm not a political person, believe it or not, and I'm not asking you to vote for or against anybody. But I am more than nervous and more than concerned about the turning away from poor people, elderly people, disabled people in our country. And the hardness that's developed and the recklessness that seems to be an everyday occurrence.

But the terrible change in our attitudes is not the only change of government. There's something much deeper here in this country. I came on an airplane, of course, the other day, and as I was waiting in one of the airports to get on one of those birds, I saw a sign that every one of you has seen one time or another. It's the poster sponsored by the United Negro College Fund. And you've heard this slogan time and time again. I... I think I wrote it down somewhat correctly. "A mind not used is a terrible

waste." You've seen it, "a mind not used is a terrible waste."

Now who's going to quibble with that? I am. I'm going to quibble with it because, while... why, of course, a mind not used is a terrible waste, that, too, is a reflection of the wrong ideas of this society. I have never seen a poster by the United Negro College Fund, or United Jewish Appeal, or the United Catholics, or Presbyterians, or Armenians, or whatever, announce that a soul not used is a terrible waste, or a heart not used is a terrible waste. We persevere everywhere in our culture, everywhere in our society, everywhere in our relationships with other people that if you don't have a fully adequate mind, it's a terrible waste, you're a terrible waste. And then not far from the surface of that complaint is the idea that you're a terrible person. That it's terrible, it's embarrassing, it's upsetting that people don't have good minds.

Well, it's better to have a good mind. Of course, it's better to have a good mind. But why is it always so terrible not to have a good mind, and we're so silent about it? All of the other attributes that human beings have. Even my own colleagues at Syracuse got into this trap.

I was keen to discourse on this poster because I gave it to my friends at the Center for Human Policy a week or so ago when they unveiled one of their posters. And they were so proud of them. They made a lot of them, very handsome poster ads, and they were proud as one is to do. They're creative and they've got the right ideas. And this poster says, "Don't think that we don't think."

Now who's going to complain about that? "Don't think that we don't think". Well, why do we have to counter attack with, "Look, don't tell us a mind not used is a terrible waste because retarded people can think." Well, yes, retarded people can think. They also can feel, they also can serve their families, their friends, their society, in lots and lots of ways other than thinking elegantly. Not that there's anything wrong in thinking elegantly, it's that we persevere so much on it.

Bob mentioned that I've been talking to this group for a few years, and it's always a special privilege to me to talk to this particular group. And I want to try to explain how...

Last time I explained it one way, last year, which I'll repeat, and this year, I've explained it another way. Last year, I think I said that there's an analogy of you people to farmers. I'll explain that.

Everybody worries about food. I'm a very early riser, so my first problem in the hotel when I check in is: when do they have room service? I can't wait to have breakfast with people at 8 o'clock. By 8 o'clock in the morning, I'm sometimes ready for lunch. And it's very important for me to start off the day with something to eat.

So it was good that in this hotel across the street they start at 6. So you know you're going to get something to eat early, but then you worry about whether the food's going to be good, warm, and on time. And is it going to be too expensive? And you have all these questions about food. And now that you've gotten over breakfast and you're sitting here maybe, who are you going to have lunch with and who's paying for it? Will you have to stand in line outside? So you go through your life worrying about food. Everybody worries about food.

Well, you know farmers worry about food in a different way than all the rest of us. And if farmers didn't worry about food in a very special way, none of us would eat. Well, in the same way mental retardation.

Everybody worries about mental retardation. I'm surprised Nancy and Ron didn't say something about mental retardation in their letter because everybody does. We worry about the mentally retarded. Well, of course, they do, everybody does. The concierge here at the hotel does. Everybody does.

But if you folks didn't worry about mental retardation and the mentally retarded in a very special way, those people would have many more difficulties than they now have. So you worry about the mentally retarded in a special way. And that's the main reason why it's so nice to be with this particular group. There are other groups, maybe even in this organization, who don't worry about the mentally retarded in a special way. They worry about the mentally retarded in the ways I worry about food.

So now the next story also connected with food, but it's another explanation of why I like to come here. A few weeks ago I was listening to a radio program, and it was one of these interviews.

Isaac Bashevis Singer, a Nobel Laureate, was being interviewed by a literary person, who said to him, "Oh, we know all of your books. We've read them all. So we don't want to talk about your books; we want to hear about your life." The person was stuck.

So Mr. Singer said, "Of course. Ask me about my life." And so the interviewer, "I understand you're a vegetarian, that you don't eat any fowl." And Mr. Singer said, "No, I don't eat any fowl." And the interviewer asked, "Well, you don't eat fowl because it's bad for your health not to eat fowl." And Isaac Bashevis said, "No, that's not the reason why I don't eat fowl. I don't eat fowl because it's better for the chicken's health." And you see? You worry about the chicken. A lot of people within the field of mental retardation, who are in the field of mental retardation because they're worried about their health. See?

You worry about the chicken's health. I mean, I can't believe anybody in this room is overpaid. I can't believe anybody in this room are getting great awards or public recognition for the work you do in mental retardation, so it's obvious. You people are actually worried about the chickens.

And there aren't all that many people in the field of mental retardation who are worried about the chickens. A lot of them are worrying about chickens but only in terms of their own health. And they're the two kinds of people in this business: Those who worry about their health and those who worry about the chickens' health. It's nice to be with people who worry about the chickens.

So it's nice for me to be here. It's great when it's all over. I might have told you this story but it came up again in another context the other day so I was reminded of it. That there is... there's craziness everywhere.

A year or so ago I was Chairman of the Honorary Degrees Committee at Syracuse University. Every year the university gives out honorary degrees to people who make noteworthy contributions either to the arts or the sciences or the treasury of Syracuse University.

Well, is that shocking? One of the candidates who was proposed by a professor of the Religion Department was Mother Teresa. So the committee had a long discussion about Mother Teresa and they read her curriculum vitae and all of that. And I thought that the committee was going to easily endorse this nomination for the Chancellor and the Board of Trustees to consider because they actually get a raft of nominations that go forward and from those that are approved, they select a few for honorary degrees.

But hers got on rocky ground. One of... one of the professors, a very distinguished professor, so he has told me time and time again, objected vehemently to Mother Teresa receiving an honorary degree from Syracuse University. And, finally, one of the members asked why. And you wouldn't believe why: She doesn't publish. Mother Teresa doesn't publish, so we shouldn't give her an honorary degree. Oh, there is silliness everywhere.

But as my old... as my old, ah, economics teacher Mr. O'Toole used to say, "Too bad about prohibition, but it's better than no drinking at all," and I say, "Too bad about all the problems that we have in the field, but it's better to have the field than no field at all." By the way, if I at the end of this talk, if there's anyone here I haven't insulted, I apologize.

One of the... things I'll get into today in this talk is, ah, relates to the music I played earlier by Carl Williams the correlate of Nazi Germany to what's going on in America, not only Baby Does but related matters. You've got to remember one thing about this Nazi Germany thing, the German citizen shouldn't be condemned because he volunteered to kill those 13 million in the Holocaust because very few of them did volunteer to kill.

The condemnation, however, is real, it's deep, it should endure because the German citizen was indifferent. You don't have to kill somebody to be condemned. And there's an analogy here too. Most people do not volunteer to kill Baby Does or abuse children in institutions or hurt other people. There are a few like that, but most aren't that way. The condemnation is that the field is generally silent. We are generally silent. We're indifferent to what we know and what we see. That's where our great fault lies. And we don't know how, I don't know how to wake people up, because, in one sense, there is progress. In one sense, things are getting better. In another sense, things are getting worse.

Okay, let's look at the news. The Baby Doe regulations were thrown out court the other day—I don't know if you know that—by a federal judge, whom you know. The government appealed, and the federal regulations were thrown out. So now hospitals do not have to report the withholding of treatment of babies. But, ah, the good news of it is that it seems to be that handicapped are getting mainstreamed.

How do I know the handicapped are getting mainstreamed? I got this in the mail just as I stepped on the airplane the other day. I took my mail to my office. I read it on the airplane, and here's an advertisement from the Group Line Books of Cambridge Massachusetts. They publish lots of books on the handicapped. Here is one: *Puppetry for Mentally Handicapped People*. No handicap to dance, created improvisation for people with handicaps. But this is the one book that I know illustrates that mobilization is... is becoming healthy and, ah, it's taking hold across the land. And the handicapped are just like all the rest of us, unfortunately, in some ways. There's a new book just published: *Yoga for the Handicapped Peo... Person*. And you know that anybody who fix... who can write a book and publish it and can sell it on yoga for the handicapped, you know our people are being mainstreamed.

Here is an article I read in the General Chronicle on Higher Education a few weeks ago: the prestigious Alaska Foundation award has just announced its prizes for scientific work. One of the people who received the award is a medical professor who received his award for research on effective vaccine against hepatitis B. I won't tell you his name because it's not fair and he's not here to defend himself. Some of you know the history of that research.

But this effective hepatitis... hepatitis B vaccine was developed at the Staten Island Developmental

Center, once called Willowbrook and it was developed utilizing mentally retarded patients at Willowbrook who, ah, whose families may have even been coerced in having their children at that institution being used as subjects.

So, utilizing subjects at an institution which the state is... had committed itself to care for, entrusted to care for, to protect, utilizing those people as subjects so that the rest of us won't get hepatitis. And then giving a prestigious award, which is oftentimes the forerunner of a Nobel Prize to the person who did that research. That's a... that's a little much.

Here's a letter to the local school superintendent of my community saying that he [*inaudible*] a problem on the school bus the other day. The children from the Rome School for the Deaf was going to Syracuse on a school, ah, they were on that bus and had a severe discipline problem with Michael D. and Alyssa S., both of Syracuse. Claimed the superintendent, neither would listen to the driver or the aide. I thought you'd get a charge out of that.

Now our good friend Wolf Wolfensberger would probably say this is probably not good juxtaposition. I'm sure he has a word for it; I don't know what it is. But in the new little journal just came out. They send me a free copy to see if want to subscribe to it or, you know, an ad on it. It's called, *The Disability Rag*. Now maybe there's good stuff in here, but why do they have to call it the *Disability Rag*? Now I'm going to get to another, I think, important central item.

A few weeks ago, there was a retrospective on William Saroyan. He's the great... was the great novelist, playwright, essayist who died a couple years ago. And everybody met in a night of tribute and a circle at the Square Theatre New York. And ah... nice picture of him here. Jose Quintero was there. He's the great director. Lots of other famous people. And it all recalled for me—Saroyan's passing—and his obituary.

This fellow wasn't taking any chances with a reporter screwing up his obituary, so he wrote his own. He knew he was on his way out, and so he wrote his obituary and he sent it around to everyone, and here's what he said... One of the things he said: "Everybody has got to die, but I always believed that exception would be made in my case. Now what?" And that's the whole thing. That's the heart of it. Everybody's got to die, but everybody here, myself included, knows for sure that an exception is going to be made in our cases. Until right at the end when we realize that maybe an exception isn't going to be made. Now what? Now we start reviewing our lives and all the foolishness and what we did and our silences and our cowardliness and our acquisitions, hunger for things.

So I want to take a few minutes of my second part of my introductory remarks. I think there's a third part of my introductory, and then I'll really get to the good stuff. I got this item in the mail a little while ago. Maybe you got one like it too, although you're probably not as famous as I am. This is from Sharon L. Taylor: "As you may already know, we have been doing some work for people who have the same last name as you do." I... I didn't know that.

Finally, after months of work, my new book, *The Amazing Story of the Blatt's in America*, is ready for printing," and I'm in it. And, ah, here she is. She's got the picture of her working at her desk in the archives researching my family, and I'm ready to send her check not to publish that book about the Blatt family. And, ah, I'll tell you, it is, ah, it is frightening to know what these people are doing because you're rich and famous.

Here's another one. I think this came just the other day. See? Congratulations. Because your phone number ends in the digits 9431, and it does, you have won the right to obtain a lifetime, repeat, lifetime subscription to Better Living Magazine for only \$4.95. Other magazines charge up to \$500 for such lifetime subscriptions, but for \$4.95 because my nu...

I would be so lucky. I maybe never even won a free magazine before, and now, look at that, just because of my telephone number. Well, this is something that is going to make some of the people in this room who are pipe smokers. This came in the mail a little while ago. I... I wish Whin Suran was alive because he'd probably know how... what to say about this one. Ah, and it's from Ben Wade Pipe Company and it says "For an investment of \$25,000 and a six to eight-month wait, you can join a small group of reasonable men, not all of them wealthy, but each the owner of a matching set of six Ben Wade Danish hand modeled pipes" Twenty-five thousand dollars for six pipes to be sold to reasonable men, not all of them wealthy. You see, we... we have meetings on the problems of the mentally retarded people, when all the time, it's our own foolishness, it's our own foolishness.

I don't know if you knew this but, ah, the 1983 National Easter Seal Society Communications Award went to Mr. and Mrs. Warren N. Becker their article "Mourning the Loss of a Son." The Becker's are the people who fought not to have to have their son, Philip Becker, operated on, and the court overturned or it upheld the earlier court decision, and Philip was operated on and despite the fact that the Becker's didn't want their son to be operated on and wanted... wanted their son to continue living until he died or would die of a severe heart defect.

But they got the National Easter Seal Society Communications Award. My good friend Wolf Wolfensberger, wrote a rather caustic letter to the Easter Seal Society for their decision, and they wrote back that they might like to make it clear that award did not or prize is not that we endorse their philosophy expressed in the Newsweek article, which surprises me greatly since you think if you've awarded somebody the prize you would be endorsing their policy.

Well even the *New York Times* is... off the bandwagon that a lot of us are on. There have been almost weekly, certainly monthly, editorials in the *New York Times* on the Baby Doe situation. And article after article, editorial after editorial, the *New York Times* is condemning those mischief makers, those troublemakers, those buttinskies for, ah, trying to, ah, ah prevent the Baby Jane Does and Baby Does of the world from being killed. And indeed the Times is going all out on this and related issues.

New York City has a new bishop, John J. O'Connor, and when he was inaugurated a few weeks ago, he gave a talk, and this too is at the heart of the matter. He said, "I always compare the killing of 4000 babies a day in the United States, unborn babies, with the Holocaust. Now Hitler tried to solve the problem of the Jewish question, so he killed them. He shoved them into ovens, burned them.

Well, we claim that unborn babies are a problem, so kill them. To me, it really is precisely the same." And the *Times* said, "How Bishop O'Connor answers the question theologically is his affair, but if he means to instruct a community at large, a change of tone would be welcome."

Now, let's look at this. I know I'm going to get into trouble with some of you by getting into this abortion thing, but I want you to try to keep your mind open on just one aspect of what I'm saying. I'm not going to discuss the merits or the demerits of abortion. And I'm certainly not going to say, as Bishop O'Connor didn't say that those who advocate abortion are like Adolf Hitler. He didn't say that. And I'm not even going to that those who advocate the withholding of treatment of Baby Doe are like Adolf

Hitler. I'm not saying that either.

What this bishop has said and what I've said from this podium last year and the year before and the year before that, and if you ask me again next year, I'll say the same thing: That in principle, in principle, Hitler's rationale is this rationale. And what did Hitler say? He said, "A life devoid of value doesn't deserve to exist. A life devoid of value. I have somewhere an article of Baby Jane Doe's parents being interviewed in one of the magazines, and it's exactly the terms they used. That this is a life devoid of value, and so it could be ended.

Part Two:

Now we come to what seems to be an escalating campaign in the media and across the country. This week in the local paper in Syracuse a couple of weeks ago: "Soaring handicapped schooling costs draws McLaughlin's fire."

Everywhere across the country, you see articles on the soaring costs of educating the handicapped. In New York City again that venerable paper, the *New York Times*, an editorial a few weeks ago: "The Chancellor's red ink" This wasn't on Alvarado and his personal red ink, this was on the fact that the city needed 92 million extra dollars in 1979 for special education. And here is another one a week or two later. "The special education spiral." The fact that special education cost... costs have soared so high that the city schools New York are being jeopardized. It's going on all over the country. And, ah, we must be aware of it.

Well, let's, ah, look at some of the professional journals. In an article by James Weber, a book, I'm sorry, *Grow or Die*, published in 1977, he quotes James Watson, the Nobel Laureate, remember the *Double Helix* book, the fellow with the critic that unraveled the mystery of the genetic code. Well, Watson has the perfect solution for getting us out of the Baby Doe trap. He's figured it out. All you've got to do is listen to him and you won't any longer have this anguish about Baby Doe. I'm quoting now. "Nobel Laureate James D. Watson, for example, believes that a child should not be given legal status until three days after its birth, so that should it be born with defects previously undetected within the womb, the doctor could allow the child to die if the parents so choose. It would save a lot of misery and suffering."

So what you could do is wait and see. I mean, it's all a craps game until the baby comes out of the womb, you see. Whether, you know, the amniocentesis is accurate, whether those 47 chromosomes really mean that the child has Down Syndrome, or whatever. So why wait, you see? Let's change the legal status of the child so the baby is not a baby, a human baby until day three. And until day three you could abort.

Another thought, in a 1981 article in *Surgical Rounds*, it's a medical journal, talks about this Baby Doe, ah, Jane Doe case. It's the simplest case of the Down Syndrome, ah, Syndrome child with duodenal atresia. "With luck, its life can be saved and then he can be trained to the point of," [are you] listening? "...of being a happy family pet." This is in a medical journal.

And this fellow is saying what's on their minds. I mean, most people won't say this in... in a journal, especially. They might say it at a cocktail party, but they won't write it. This fellow's writing what's really on their minds. At best, you've got a family pet.

And where does this all go back to? A mind not used is a terrible waste. You see the connection

everywhere you go, even in the most altruistic groups and from the most altruistic messages. You're being bombarded that a mind not used is a terrible waste. It's a tragedy. It's a disaster. It's a horrible thing. It's okay if you're a thief, if you're immoral. I mean, after all, if all of the thieves and immoral people are gathered up by the government, I mean, who'd be running it? But a mind not used is a terrible waste. So what could these people be? They could be family pets.

This October in *Pediatrics* journal, there was an article on what to do with spina bifida children. Spina bifida is a, is an important part of the discussion here because the children need to have spina bifida or Down syndrome, those who we're having all of these arguments about.

And this article in the October '83 issue of *Pediatrics*, which is the journal for pediatrician, [a doctors formulated, I believe a Dr. Shore,] And who was this Shore? He developed a formula on the quality of life". And you... you determine quantitative factors representing natural endowment or the physical and intellectual, and then you quantify contribution from the home and the family, and you quantify the contribution from the society, and you put it all in this formula and if it reads as a certain score, ah, then you don't snuff out the life, but if it goes below that score, you could.

You've got it all here. You can have a little program. You don't even have to figure it out. You put a little program in and you put the factors in it, and, ah, you can make a decision.

So, that's what we've got here. That's the news. Now are things better? Sure, they're better. Are they different? Sure, they're different. But the more things change, the more they remain the same, as you all know.

I had a great mentor. He used to try and teach me that the only thing we learn from history is that we don't learn anything from history. But if we could learn from history, we might know something about this paradox that we don't know now. If we could only think of mental retardation, at least in some sense, as an invented disease.

It's like this thing with Diane Arbus, with the photograph. It's invented in the sense that you can't understand it only by understanding the individual. It's not like pregnancy where the gynecologist examines the individual and you know whether the person is pregnant or not. You can't understand mental retardation only by understanding the individual.

You've been to meetings, maybe this week, on the nomenclature in mental retardation, the terminology in mental retardation. And it was a tremendous revolution on the terminology in 1959. That was, I think, the most important change in the definition of mental retardation. And in fact, in the conception of this thing. We're here meeting on this thing.

Before 1959, as many of you know, mental retardation was by definition constitutional, something in the head, incurable, irremediable, permanent. Something in the central nervous system that's permanent and irremediable. And whether you picked Tred(?) Dole or you're picked up Edgar Doll or you picked up Jane Wallace [name] or the AAMD nomenclature itself, they all said the same thing prior to 1959. That mental retardation is a constitutional condition of the central nervous system. It exists from birth or early age. It's incurable, irremediable. And so one couldn't be cured. One couldn't be changed. It's permanent.

Anybody that was changed from a state of mental retardation to a state of normalcy couldn't have been

retarded. The person would have had what we once called pseudo-mental retardation, because by definition, anybody who did change wasn't retarded. So there was never a case of cure, there was never a case of even amelioration because amelioration and cure were by definition not possible. And anybody who did change in any remarkable way was incorrectly originally diagnosed.

In 1959, the Heber definition said that mental retardation was sub-average general intellectual function, and we made no presuppositions about cure or about amelioration. Fundamental change. And how did we accomplish in the laboratory? Scientists, Watson Crick who? No. You people sitting around some hotel room, probably tired, too much to drink, they changed the definition.

Well, it wasn't quite that simple, of course. They were highly motivated through the years, about it, politics involved as well as values and sign of the times, and they finally changed the definition. Well, a lot of people didn't like that definition in 1959, both because there were some who kept saying, "Well, what about the Down's child? Or what about the child with microcephalus or phenylketonuria or cerebral palsy in retardation? Those people aren't going to change."

Well, but they had the argument then too what about Helen Keller? She was as defective as any of them and she changed. And what about that large, large group, maybe 85% of those who are mildly retarded, so... so-called cultural familia, what we once called cultural familia. Some of those people, lots of those people, most of those people when they leave school, they get jobs and have family, they become indistinguishable in our community. They changed.

I mean, they were once mentally retarded and special class and now they're working and having families. They changed. They're normal. So we're changing the definition. Well, so they didn't like on... Some people didn't like it on the cure factor. Other people didn't like it on the IQ ... Q criteria. Because the 1959 definition said that you need two... two characteristics to mental retardation: Psychometric deficit—low IQ—and adaptive disorder.

And by definition, that committee Heber-Weber said that the psychometric cutoff would be one standard deviation on the wrong side of the mean, less than 85 IQ. If you have less than 85 IQ, you're in the ballpark. You could be considered to be retarded. And with that low IQ, less than 85, in combination with an adaptive disorder, or maturation or learning or social adjustment, you could be identified as mentally retarded.

Well, we've argued about and persisted until 1974, I believe, because 16% of our ordinary population who have less than 85 IQ. And so what we once thought was sort of a cottage industry with 3%. You always heard this 3% mentally retarded, and that comes this IQ cover for 75. Now we have an explosion of not 3% to theoretically could be psychometrically retarded to 16%.

So we had a big argument, 3%, 16%, maybe something in the middle, something below, and they've had this argument for years. Now what the hell does that have to do with mental retardation? I mean, let's face it. Is there somebody in this room who (is) pregnant and you don't want to be pregnant? You're not waiting for the gynecologist to change their definition. It's not going to change your state of pregnancy.

But mental retardation, everybody was waiting around for this committee to decide whether it's an 85 IQ or a 75 IQ. So there's something different here. Well, they finally did decide. Finally in 1974 they decided that, no, it's not 85 IQ or below who are psychometrically retarded. Not one standard deviation,

two standard deviations, 70 IQ... which changed the theoretical incidence of psychometric retardation from 16% to 1%, which cured more retardation more than science did since the beginning of time... without ever having to treat anybody.

Nobody was ever treated. I mean nobody was ever treated for IQ in this way. We changed the definition. And so when I say mental retardation is an invented disease, they say, "What do you mean it's an invented disease? There are people who are mentally retarded." Of course, there are. We invented the disease and we invented the categories and, of course, we have people in them.

I mean, a college student is an invented status. Anybody here who's been to college is a college student or was a college student. Democrats? You registered as a Democrat, you were a Democrat. What else do we know about you? Not much.

There are lots of invented diseases. Old age is an invented condition. It's taking on proportions of big industry. When I was a young fellow, my grandmother used to live with us until she passed away. She lived with us for eleven years. I never knew that when we were nice to my grandmother, my parents were very nice to her. She lived with us as a part of the family.

I never knew we were gerontologists. I never knew that. I never knew there was such a science that understood old age and treated it. I never knew those things. I thought it kind of natural when people are old that when one of the partners had to die and they couldn't live alone, they'd go to live with their children. And, ah, but not today. Now we know more about old people than ever before in history. We know about strokes. We even know how old people think. We know that they don't think as quickly as some young people but they have more wisdom under certain conditions. We know about certain diseases, what people can get things. We know so much about old people.

You'd think with all we know, they'd be able to live in the ordinary community a lot easier than fifty years ago when we didn't know anything. But yet the more we know, the more we seem to be secluding them into special places. So old age is invented disease. They're a science, gerontology. We got conditions, geriatric. We've even got clubs, Golden Age. They've got a little card.

Mental illness is an invented disease. Read the Thomas Archer's book "There's a Manufactured Madness." That lays out not only how mental illness became a disease, how it took over so many of the trappings of religion substituted... psychiatry substituted for religion, but you also learn so much about mental retardation.

A few years ago the American Psychiatric Association had a debate at their annual meeting on whether homosexuality was a sexual orientation disturbance or whether it was a mental illness. And after the debate, they asked the members, the delegates, to vote, and the delegates by vote decided that it was a sexual orientation disturbance. That is, they voted what was once a disease into now a... an orientation disturbance. So they... they cured the disease by vote. A hundred years ago people who masturbated were put in mental hospitals. It's in [Dorcher's] History of Mental Hospitals. This is a psychiatry book. They were... they were judged to be mentally ill for that disgusting ab... aberrant behavior.

Now that same profession, psychiatry, is taking what was once the disease, masturbation, and now it's the treatment, and they're advising... advising some of their hyper-anxious, ah, clients to engage in that practice as a treatment to prevent mental illness. In certain families, manual work... is an invented disease. Manual work. "Mom I don't want to go on to college, I want to get a job as a carpenter's

apprentice.” I can tell you, the mother would rather have the child have, ah, [Laughs] a dreaded disease that he could be cured of than go on to be a carpenter instead of going to a university. I mean, that is a decision that can cause terrible, terrible family problems. It could lead to the family disowning a child, throwing him out of the house. Not talking about him anymore. “Charlie won’t go to the university. He wants to be worker with his hands. What’s the matter with him?” So what do you do?

And what do we characteristically do that we do with invented diseases? Do we banish them? People who have them, we banish them since the beginning of time. We banish old people now. We banish the retarded. We banish the mentally ill. We banish Charlie who doesn’t want to go to college, who wants to work at McDonald’s or with his hands. And once upon a time, banishment was a capital punishment.

Socrates didn’t receive the capital punishment when he drank the hemlock. That was elective punishment. Capital punishment in ancient Athens was banishment from the society. And we do a lot of banishing here in our society. We devalue, and you and I can recount many, many stories of how people are devalued for these invented diseases. We have hatred and fear. I once wrote a paper on stories we tell about people, and it was titled something like “How to Destroy Lives by Telling Stories.”

And what I tried to say in this little paper was be careful about the stories you tell about other people because you could destroy them. And I suggested that nobody should ever tell a story about someone else that that person doesn’t want to have told about him or wouldn’t tell on himself.

Everybody is entitled to his own story about his life, even a fellow in a mental institution who thinks he’s Napoleon. Now, he is Napoleon. He may not be the Napoleon you think about with Josephine, but he’s Napoleon. You need to be careful about stories you tell about people because they can hurt them. I mean, King Farouk, you remember. He was the Egyptian King before [Gogda]. He, ah, never felt he had a... a... good offspring because they were all girls and he wanted a son to inherit the throne, so his story about his children was a very negative one.

Part 3:

And so what am I saying? I’m saying that we’ve got... a field here with ostensible progress.

Mainstreaming, that’s a big issue today. We have had sessions at this meeting, other meetings, on the progress in mainstreaming, on where we go from here and what we’ve learned about mainstreaming, and we continually ask science to inform us about how it’s working or whether it’s good. And I think all of those sorts of questions are relevant and could be helpful. But the fundamental question on mainstreaming is whether we want it or not. That’s not a scientific question.

And we can determine that handicapped children, retarded children learn more, better in a mainstream class than in a segregated class. But it’s a matter of fact we can also determine that handicapped children under certain conditions or certain kinds of handicapped children learn more or better in a segregated class than in a mainstream class. And the same goes for deinstitutionalization.

Now there’s a big argument about that federal legislation that’s up for grabs now, community programs. And you have hearings and you’ve got all kinds of experts talking about the value of deinstitutionalizing people, creating community programs. Value in terms of learning, of productivity, happiness, economy.

Oh, I’ve heard many times that it is less expensive to have people in desegregated environment than in

an integrated... I think that's true. I think... I think all of those things I personally think are true. But if this field made a mistake, a fundamental mistake, I mean a deep one on the strategy, a strategic mistake, it was to argue the mainstreaming in, ah, issue and the deinstitutionalization issue on the outcomes for the clients' behavior for those residents or those children in school. They'd be smarter, or better, or happier than they were in the other kind of environment, whichever side of the issue you're on.

Why was it a mistake? Because the purpose of mainstreaming, fundamentally, centrally, the purpose of deinstitutionalization is to give an individual an opportunity to live, work, and grow in an ordinary environment.

The purpose of deinstitutionalization is to free the person. The purpose of mainstreaming is to commit the person to live and work with other children in his community. That's the fundamental purpose. All the other things are important, but all secondary to the fundamental purpose. You will find scientific reasons to mainstream where the institutionals are deinstitutionalized. Either you want to or you don't want to. Now we could, if we wanted to, we could mainstream everybody in America tomorrow and deinstitutionalize everybody in America. That's how mainstreaming is a much different kind of problem than cancer.

You can't cure all the cancer patients tomorrow, but you could mainstream everybody tomorrow if you wanted to. You could deinstitutionalize everybody tomorrow. You say, but are they going to grow more, are they going to live better? Are they going to be exposed to more dangerous situations? Maybe. Maybe they will. And I'm not suggesting that you foolishly dump, or whatever word they use. But I am saying that the issue is not how much better off the person is going to be. That's been the mistake.

Now some of you by this time, for maybe lots of other reasons, but for this reason too, are a little angry at me because, I mean, how could I say that? How could I say that it's irrelevant whether somebody could learn more in the integrated class or the special school. Why is that irrelevant? In one sense it isn't irrelevant. Of course I want the children to learn more, and I believe that you can learn as much in an integrated class as in a segregated class. But it's irrelevant in the same way that it's irrelevant in your lives.

Now think about your own lives. I mean you're sitting here, listening to this. You'd probably be much better off in your room reading the Gideon's Bible or out taking a sunbath. It's good for your health. Or if you really wanted to make your life most useful, most productive, where you're going to get every last ounce of your capabilities, you're not going to go to a banquet tonight and drink too much and eat too much, and maybe even do some terrible things that you'll be sorry for the next morning. You're going to go home and get a good night's sleep, get up in the morning and go to the public library tomorrow morning. You're going to spend six hours every day in the public library. You're going to learn more, you're going to read more. You might even write a little bit.

So maybe you'll get promoted. So stop your drinking, stop your carousing, stop your fornicating, stop doing all those terrible things that people do. Why don't you stop those things? And you're saying, "Who the hell are you to tell me to stop?" All right? So people do things. People are free. So too them.

That's the issue. What kind of society do we want to create? I mean that's the whole purpose of this community living matter. It would be a disaster if you try to make a case that community living is going to teach retarded children better than institutional living. I think it will. I mean, I've never seen anything

in an institution that can't be duplicated in a community and probably less expensively, but that isn't the point. Even if the institution can teach you better, certainly make you safer. You're probably not going to get hit by one of these automobiles crossing the street here as you go from one hotel to the other if you're back in the institution. But that's not the point. Freedom is the point!

Well, believe it or not—it's five minutes to twelve—well, time goes very quick when I'm having a good time. The other part of my talk, which we'll save for another year. And I wrote it just for this group, but that's all right. [Go ahead] It can hold. I, ah, I've long worried and thinking about it. Why don't people listen to good advice? I mean, every year I gave so many people such good advice. I can't understand why people don't listen to me.

Well, I finally figured it out. I tell people how to change the world. I think that was my talk two years ago, but we don't change the world. Now if that isn't impertinent. I tell people how to change institutions, how to change the lives of the retarded. I give all kinds of wonderful advice, but nobody listens.

And the reason nobody listens is a good reason. I wouldn't listen either if I were you. People only listen to advice, especially when it's these broadsides, somebody getting you who you don't know or don't know very well and harangues for an hour or hour and a half, why should you listen to that advice, especially about mentally retarded people? That's another example of a secret in a secret, you know.

And especially when it's such conflicting advice, because you go next door and something is giving a speech on institutionalizing for protecting health and life and liberty and the American way. I mean, so why... I mean you finish my speech and you go the next place. So there's a confusion. So I decided that today, which I won't get to, except for maybe five minutes, the advice that I was going to give you is not how to change all the retarded people's lives, their lives, but how to change your life. How to change your life. And believe it or not, I've got about, oh, a dozen pages on how to change your life, but I'm only going to talk about five minutes.

But here's I wanted to say. When you get up in the morning, the first thing you ought to do is do something for yourself. Now if you like to write, then write. It might get you promoted. If you like to run, then run. If you like to eat, eat. The only thing you shouldn't do when you get up in the morning is go back to bed. You ought to do something for yourself. And, ah, the reason why I think you ought to do that is it makes it easier to endure the rest of the day.

People get into crazy days. I know the kind of work you people do. And so as somebody's assaulting you for no reason, really, not in your mind anyway, you'll remember that you already did something very wonderful for yourself this morning, you wrote a nice page, or you ran, or you ate like a fool. But, but, you know, you did something for yourself, something you like to do. And that, to me, is very important. So the first thing I do when I get up in the morning, I write. Now if I liked to run, which I don't, I would run. See? If I liked to read, I'd read. But the first thing in the morning, you've just done something for yourself.

Now the second thing is before you go to bed at night, it's nice to remember what you did for somebody else because that makes you feel good about sleeping through to the next day and maybe somebody will let you sleep and you'll be able to go on for another day. And so you ought to do something for yourself when you first get up and then do something for somebody else before you go to sleep.

Now another thing you could do for yourself is try not to let people know or think that they're

expendable. Now I know nobody consciously does this, especially in our work, but we do it unconsciously. I saw it the other day and that's what got me started on this. Somebody was going on vacation in our office. So everybody hovered around the person and wished them well and said, "Don't worry, we'll get along fine without you. Have a wonderful time. Don't rush coming back. You know, we're going to do great without you."

That's not what they want to hear. And when somebody retires, they don't want to hear, "Don't worry, nobody's expendable every... ah, is unexpendable. Everybody can be replaced." People aren't removable parts, exchangeable parts. And we let people think they are. And we let the closest people to us think that they're expendable and exchangeable.

And it is rather silly that so many of us worship these football players who make forty million dollars and these and... and Michael Jackson and... and... the rock stars and the movie stars. People we don't even know, we worship them. Robert Redford. I mean, how many people in here, even the fellows, I mean they're jealous but they worship him. And the women, everybody worships Robert Redford.

Now, how can you worship Robert Redford and in so many ways let people like that know you worship them and the closest people in your lives you never let them know you even care about them. I don't understand that. There's a reluctance to let people know that they're not expendable. That if they go, they can't be replaced. And even when they go on vacation. "Look, have a wonderful time, Agnes, but I don't know how we're going to get along without you." That's okay to say that if you, if you think that."

Now this is for the busy executives here. I'm going to have to tell this to some of my friends who are professors. My father used to tell me that if you need more than one job, you have the wrong job. Now I hope everyone in this room becomes rich, famous, and beloved. Administrators, professors, doctors, nurses, whatever you do. But if you really have to go out and give that speech or take that consultancy, because you can't get along on the job you have if you really have to do that and all those other things that you don't want to do, you've got the wrong job.

And I'm going to say something I said a year or two ago and maybe end it with an elaboration on this. I've got a nice full crowd here. There are a few empty seats, but I've got a nice full crowd here. And, ah, had Bob put this meeting in one of those big barns, you know, one of these big plenary rooms, this crowd would have been sitting in a little corner, and I would have come in and Bob would have been a little embarrassed.

And he would have said, "Gee whiz, nobody came, Burt, what's the matter with you." And I would have felt... nobody came to my talk. But today I feel everybody came to my talk. Everybody from AAMD came to my talk. And any... anybody worthwhile at AAMD is right here now. We can... we can hardly fit, but maybe we've got room for a couple people but, you know, we needed a couple empty seats so people could have elbow room. So everybody nearly came.

Now... now how did I come to that conclusion? It's like the 23rd Psalm. Remember? My cup runneth over. That's really the key to making your life better after keeping those retarded kids. Let's keep everyone. That's why nobody else could judge whether somebody's life has value.

It's that 23rd Psalm, that's the key to the whole thing. What does it mean, "My cup runs over"? It means that the container is just the right size for the contents. And, you see, it spills over, it's rich, it's full. Now if you had a caldron... Some people's lives are caldrons. There's never enough. It's always

empty.

That's why sometimes at the university you see a big shot, a dean, or a famous professor walking around as if it's their last day on earth and they're down in the dumps. And the fellow pushing the broom in that building, he's whistling, he's got a smile on his face. Now that guy pushing the broom knows something about life that the professor doesn't know. That fellow pushes the broom... pushing the broom has a cup that's just the right size. His life is full.

And the smart people, whether they're professors or doctors or teachers or social workers or people who work at the vocational workshop who just came out of the institution, smart people have figured out what size cup they need. And they've figured out a way to fill it. And the size of the cup is never bigger than the contents, so it's always full and rich. And that's what I'm saying, if you have to keep going, to do more, to get more, not because you want to do more but because you don't have enough, then the cup is too big. And it's not that you'll ever have enough to fill the cup, you have to change the cup or the size of it.

Well, that's what I have on my mind on the progress of mental retardation. Everything has changed, sure. It's better, it could be a lot better. And I remain optimistic. First, because the people like you who have spirit and soul and even some have minds that haven't been wasted. I also remain optimistic because I think I share with you this idea that you judge progress in our work, you judge progress in your lives not so much by how much others have changed and gotten better, a little better, but how you've changed and gotten a little better. And if you judge your work and your life and even your field in terms of how you've changed and gotten a little better, you may be able to see some daylight and you may be able to endure. I want to wish you all a good conference, and, ah, thanks again for inviting me.

[END]